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ABSTRACT

In exploring myths surrounding the development of persons with Down syndrome, this paper discusses briefly the characteristics of Down syndrome, the origins of the myths, the status of the myths in light of current empirical research, and reasons why developmental psychology has clung to some essentially counter-developmental assumptions. Emphasized is the myth that individuals with Down syndrome exhibit uniformity in their physical appearance, musical ability, personality, and limited intellectual development. It is argued, on the basis of historical analyses, literature reviews, and the results of a longitudinal study of children with Down syndrome, that many of the ideas about these children are not strongly supported by empirical evidence. Reasons are cited for the continuance of the myths, including: little systematic research exists, much of the research was conducted in institutional settings which perhaps exaggerated the sense of homogeneity, and recent evidence seems to have been subjected to a process of oversimplification. (JDD)

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Down Syndrome and Developmental Mythology

by

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PROGRAMME

DOWN SYNDROME AND DEVELOPMENTAL MYTHOLOGY

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Developmental psychology incorporates a range of beliefs and assumptions about the processes and products of development. The present paper focuses on some of the ideas that have arisen concerning the development and characteristics of children with Down syndrome and analyses their bases, in fact. It is argued, on the basis of historical analyses, literature reviews and the results of a major longitudinal study of children with Down syndrome, that many of the ideas about these children are not strongly supported by empirical evidence. Rather, they represent a mythology about children with the syndrome. In particular, the myth of uniformity seems to have persisted from the earliest clinical descriptions to the contemporary literature. This myth subsumes ideas of limited variability and high stability of developmental characteristics. The paper ends by considering the extent to which similar mythologies may be evident in other areas of developmental psychology.

Developmental psychology incorporates a range of beliefs and assumptions about the processes and products of development. Literally defined, development is an unfolding process (Sameroff, 1983, p.237). In this literal sense, development is seen as a process similar to the gradual emergence of the image on an exposed photograph. With the passage of time, the image becomes clearer although it may be possible to glimpse the later form quite early in the process of development. As Sameroff argues, however, the analogy does not embody any notion of transformation as the final image was held to be there all along. This concept of development stems from the idea of preformationism. This idea, which emerged in the thinking of Classical Greek scholars such as Aristotle, essentially assumes that the fertilized ovum carries all the parts which will correspond to the adult form. In contrast, an alternative view, again embodied in Aristotelean writings is the idea of epigenesis. In this view, the form is not present from the outset, but, rather, is constructed from the interaction of the basic developmental raw materials with the surrounding context.

In the epigenetic view, the concept of change is a central definitional feature of development. Cairns (1978) for example defined development as "...the dynamic organization of behavior over time, from fertilization to death" (p.5). Developmental psychology, therefore, has a dual focus on "(1) the origins of an activity or pattern of activities, and (2) how an activity is maintained or changed in the life history of an individual organism" (Cairns & Ornstein, 1979, p. 5). Variability is a basic feature of development and may take several forms. These include, first, species general or normative changes in behaviour and competence, second inter-individual differences, third intra-individual differences and, finally, extreme deviations or exceptionalities.

In this paper I will argue that the press to uniformity and stability has been particularly well entrenched in the area of exceptional development. Whether one talks about those at the gifted or talented end of the spectrum or those with disabilities, there seems to be a press to generalise, and as a result, regard all members of a group or category as if they were identical in their characteristics, rates of development and long-term outcomes. Once identified, the presumption seems to be that the course of

development is somehow encapsulated in the diagnostic label, in the same way that the whole image is trapped in the photographic negative. As Stoneman and Brody recently commented:

> The assumption has frequently been made that [disabled] children are a homogeneous group, resulting in studies which lump together children with a wide range of functional levels, ages, and secondary handicapping conditions. (p.114).

Conditions with a genetic base seem particularly prone to these unifying myths Down syndrome is the most prevalent chromosomal abnormality leading to some degree of multifaceted disability including, medical complications, visual and hearing problems, intellectual handicap, speech and language disorders, gross and fine motor problems and social and emotional difficulties. Specifically, I want to explore some of the myths surrounding the development of persons with Down's syndrome. To do this I first want to discuss briefly some of the characteristics of persons with Down's syndrome, second briefly explore the origins of some of the myths, third examine the status of the myths in the light of current empirical research and finally, offer some suggestions concerning the reasons why developmental psychology has clung to some essentially counter-developmental assumptions.

What is Down's Syndrome?

Down's syndrome was first reported by John Langdon Down in 1866 but it was not until 1959 that the French cytogeneticist, Lejeune established the chromosomal base for the condition. Even cytogenetically, there is not a single chromosomal abnormality but three types of disorder. The most prevalent, Trisomy 21 is present in approximately 96% of cases. In 3% of cases the condition involves an unbalanced translocation of material from one chromosome to another (for example from the 15th to the 21st) Finally, in approximately 1% of cases the condition involves mosaicism (where only a percentage of cells are chromosomally abnormal).

It is now clear that the genetic effects of Down syndrome are very complex and contribute considerably to the variability of the condition. The particular genetic effects seem to be localised at one site, 21q22 at the distal part of the long arm of the chromosome. Genes at this site seem to have a regulating effect on the operation of those on other chromosomes, in part explaining the extensive and widely varying physical effects of the condition. Added to this is the growing evidence of the variation contributed by the varying developmental environments.

As a result of the underlying genetic variability, the physical characteristics of persons with Down's syndrome vary considerably (Smith & Wilson, 1973) For example, approximately half will have a heart defect, compared to about 1% of the general population. Estimates of the incidence of hearing problems range between 60 and 80% (Davies, 1985) Visual problems of very varied type and degree are reported in children with Down's syndrome (Millis, 1985).

The Origins of the Myth of Uniformity

The origins of the myth of uniformity of the syndrome are interesting to ponder. Prior to the discovery of the chromosomal base for the condition, it had been thought to be an atavism, or racial "throwback", and had been labelled "mongolism" ,by Down (1866), or Kalmuc[sic.] idiocy, by others such as Fraser and Mitchell (1876). Reflecting the prevailing knowledge at the time, Down had assumed that, because of the "Asiatic" cast of their eyes, persons with Down's syndrome were atavistically linked to the oriental races. He wrote:

> I have for some time had my attention directed to the possibility of making a classification of the feeble-minded, by arranging them around various ethnic standards...I have been able to find among the large numbers of idiots and imbeciles which come under my observation...that a considerable portion can be fairly referred to one of the great divisions of the human family other than the class from which they sprung...A very large number of congenital idiots are typical mongols. So marked is this that, when placed side by side, it is difficult to believe that the specimens compared are not children of the same parents...It is difficult to realise that he is the child of Europeans; but so frequently are these characteristics presented that these ethnic features are the result of degeneration...They are, for the most part, instances of degeneracy arising from tuberculosis in the parents....(Down, 1866, pp.212-215)

On the basis of physical appearance, Down assumed a uniformity in the cause and the developmental manifestations of the condition. Since the discovery of the predominant cause of the condition, Trisomy of chromosome number 21, the emphasis on uniformity, if anything, has been strengthened.

Despite a growing awareness of the heterogeneity of the condition, the myth of uniformity remains. A far from random survey of texts over the years since 1866 underscores the point. The emphasis for writers, with some recent exceptions, has been to describe the syndrome in terms that imply that the characteristics of all children with Down's syndrome are essentially identical.

Physical appearance: For example there is still a tendency to assume that they "all look alike":

> The concurrent constancy of a characteristic condition of mind with a characteristic condition of the body is what gives interest to this form of idiocy. The mental state is as distinct, as peculiar, and as steady as the physical. If the fifty-four were brought together they would be found to resemble each other strikingly in personal appearance. But more than this, they would also be found to resemble each other in character, in capacity, in likings and dislikings, in habits, in defects, in aptitudes, etc.
> (Fraser & Mitchell, 1876, p. 177)

> They resemble one another and all promise much and achieve little. They are imitative and learn a little in this way, but they never cease to be imbeciles.
>
> (Kerr, 1926)

> The clinical characteristics of Down syndrome vary but are similar to the extent that most individuals with Down syndrome resemble one another more than they resemble family members.
> (Drew, Hardman & Logan, 1984, p.186)

Musical ability: As a counter to the pessimistic realities of the disabilities associated with Down's syndrome, some compensating positive characteristics frequently have been referred to over the years. Among these is their rhythmic ability and fondness for music.

> Mongols are more difficult to teach. They have very good powers of mimicry and will imitate animals or sometimes persons very closely, being in this way often very amusing to other children. They are usually fairly happy and contented, but many of them are of low grade and not very many are found suitable for treatment as feeble minded, being more often

of the imbecile class. Another curious point is that they are often very fond of music moreso than are other children.

(Lapage, 1911, p.109)

Sometimes in children who are mentally deficient certain areas of mental development and function are more acute than others. Occasionally these areas are even more strongly developed than in normal people. Most children with Down's syndrome have an increased sensitivity to music. They love rhythm and dance, and often are good at playing simple musical instruments, percussion and rhythm instruments especially. Listening to music, singing, dancing, or playing an instrument brings them great pleasure.

(Smith & Wilson, 1973, p. 40)

The syndrome personality: Another generally positive aspect of persons with the syndrome relates to their personality.

In general, they are cheerful, friendly, outgoing, and active (even boisterous at times), though many have a stubborn streak.

(Smith & Wilson, 1973, p. 39)

> The typical image of a retarded person is that of a Down syndrome child with the striking features (pudgy face and limbs, protruding tongue) characteristic of the disorder. A casual observer might add that the child's speech might be slurred, that the child might have a pleasant personality, and that heart defects are possible. The presence of organic defects, and corresponding physical sequelae, are important to this general view.
> (Zigler & Hodapp, 1986, p.8)

Limited intellectual development: Against these positive attributes of fondness for music and pleasant personality, at least in childhood, typically there is painted a rather bleak picture of uniformly limited intellect and progressive developmental deterioration.

> Even in the milder cases the clumsy and ill-formed condition of the hands usually precludes any kind of work requiring dexterity and most of the persons do best in the garden or on the farm.
> (Tredgold, 1914)

> There is no chance of the mongol imbecile ever being able to earn a livelihood or to look after himself altogether. Nevertheless, it is no small gain if he can learn to do anything that is useful as it gives him a purpose in life and is a source of pride and pleasure. Much can be done to make the lives of these children happier by simple instruction and amusement as is provided in our large institutions for the feeble minded.
> (Still, 1920)

> Mongols are usually placid and happy idiots whose bodies bear ample evidence of the widespread constitutional nature of their abnormality. Idiots are wholly dependent. They cannot be taught to feed themselves or to keep themselves clean. Nor can they recognise other people or communicate with them except in the crudest and most primitive way. They are in fact considerably less intelligent than domestic animal.
> (Stafford-Clark, 1973, p.91)

> People with Down syndrome have an extra twenty-first chromosome, which causes them to have characteristic physical features: almond-shaped eyes, round heads, and stubby hands and feet, among others. More important, they show some degree of mental retardation, although usually not enough to keep them from learning to manage a good deal of their own lives or from holding routine jobs; nor does it prevent them from having agreeable dispositions.
> (Seifert & Hoffnung, 1987, p.91)

Among the initial sources of these ideas are the original report by Down and a paper published in 1876 by Dr John Fraser and Dr Arthur Mitchell. (The latter had the distinction of possessing the endearing title, Commissioner in Lunacy.) Their paper presents case material related to Elizabeth Meldrum who was "admitted 18th Feby.,

1875; from Ferryport-on-Craig, Fife; died, 29th March, 1875", aged 40years. In Fraser's words, "She was an illegitimate child, and parturition at her birth is said to have been normal. Her mother, who died some time before the patient's admission into the asylum is said to have suffered remorse and mental pain during her pregnancy, and to have expiated her sin by constant and affectionate care for her unfortunate offspring" (p.170). They provide the following, fascinating glimpse into one of the origins of the myths that have endured over the last 112 years:

> Her intellect may be said to have may be said to have been that of child from a year to eighteen months old. She could not speak, but she uttered sounds with volubility as if she were busily speaking, and when in anger she did this with emphasis and vehemence. Her sight and hearing were good. She remembered the faces of those who were kind to her, and of those who annoyed her, and sought notice from the former and avoided the latter. Her chief characteristic was an affectionate disposition. This was evidenced by her kind, contented, and happy expression, and by her grasping the hand of anyone who took notice of her, patting it, and putting it to her cheek. At times she had the peculiar habit of putting one's hand on the back of her head, and indicating that she wanted it smoothed.
>
> Another characteristic was her love of decoration. Any bright article of dress she wore with jealous care, and drew every one's attention to it. If any other patient had anything gay on, she always pointed to it.
>
> She is reported as being very fond of music.
>
> She continually sat in the corner of a bench next the fire, with her feet under her. She has no sense of modesty, and her habits were dirty. She had a great hatred of water, and her struggles against being bathed were strong and persistent. On admission she was extremely dirty, and I attribute the cause of death, acute pleurisy, to the constant bathing which was rendered necessary by her habits.
>
> The description of the mental state would have been fuller, had the patient been longer under observation. She died after about six weeks' residence in the asylum.
>
> (Fraser & Mitchell, 1876, p.171)

The Status of the Myths

Against this background of beliefs about the essential homogeneity of those with the syndrome stands a growing literature pointing to the heterogeneity of the condition and the absence of empirical confirmation of some of the most enduring "facts" about Down syndrome.

Appearance. While I cannot report empirical data here, the following photographs, presented with the permission of the families, show the variation across individuals and the strength of family resemblance.

[Show Slides of Siblings here.]

Musical ability. Stratford and Ching (1983), studied the rhythmic ability of three groups of children: those with Down syndrome, those with intellectual disability, not attributable to the syndrome and those without any identified developmental problems. The groups were matched on mental age. Briefly, the researchers found no significant differences between the Down syndrome children and the normally developing group, although the performance of the Down syndrome group was significantly higher than the performance of the non-Down syndrome, intellectually disabled group.

Personality and temperament. In this area, work by Pat Gunn (1985) has convincingly demonstrated that there is not a syndrome specific temperament. Rather, there is variability, with some children showing predominantly "easy" characteristics and others the constellation of "difficult" characteristics. Further, the differences in temperament ratings were related to the nature of the interactions of children with significant others.

Intellectual ability. Again, work from the Schonell Centre Longitudinal Study of Down syndrome challenges the enduring myth of a uniform pattern of intellectual ability terminating in a plateau in development at a mental age of ?????.

[Present Plateau Slide Here.]

Prospective data indicate that their is continuing linear development and very wide variability in the levels of performance across the sample. In addition, there seem to be a range of developmental trajectories with in the sample.

[Present Trajectory Slide Here.]

And Yet the Myth Remains.....

Clearly the myth has remained for a variety of reasons. First, until quite recently, there has been very little systematic research. As a result, the early clinical descriptions seem to have been accepted uncritically and perpetuated, perhaps inadvertently. Second, much of the research was conducted in institutional settings which perhaps exaggerated the sense of the homogeneity of those affected by the syndrome. Finally, recent evidence seems to have been subjected to a process of oversimplification, particularly by writers of text books.

One of the most powerful oversimplifications concerns the search for average or modal characteristics, to the exclusion of consideration of the variability, both between and within persons with Down syndrome. This problem is not only restricted to the study of Down Syndrome, but reflects a pervasive tendency in developmental psychology to seek uniformity and constancy, rather than variability and change. For some time, however, Kagan has argued that there is a bias in Western developmental psychology towards seeking stability and uniformity rather than change and variation.

> Eastern scholars see more impermanence in nature: because living systems are always changing, much of tomorrow will be independent of today. But the Western mind, frustrated by the inexpressible flux, demands some almost frozen moments - either in the form of hypothetical entities that do not transmute, principles that impose uniform regularity, or if these cannot be defended, at least periods during which the rate of change slows (Kagan, Kearsley & Zelazo, 1980, p.27)

As I have argued the press to uniformity and constancy may be particularly prevalent when biological determinants are emphasised, as in the case of Down syndrome. In biology, Oyama recently underscored the inappropriateness of equating biological determinants with immutability:

> we tend to focus on constancy rather than change ... though, change and variability are as basic to biological processes as uniformity.
>
> (Oyama, 1985, p.24)

Finally, the process of homogenization may be subtle, and partly contributed to by the poverty of language to handle the subtleties of individual differences. For example, the term "Down syndrome persons" conveys a very different meaning to the term"persons with Down syndrome". The former immediately places the semantic weight on the syndrome, the latter on the person. Perhaps the myth of uniformity will continue to endure for as long as we remain unable to go beyond categories such as "disabled" and "normally developing", and for as long as we are prepared to accept the excess semantic baggage they carry. To this extent, perhaps the lessons of the struggle for gender equity require further generalization, not only to disability research but to the field of developmental psychology, at large.